

South Carolina Department of Disabilities and Special Needs  
**INVENTORY OF AGENCY AND COLLABORATIVE PREVENTION INITIATIVES**

**FY 2011**

The mission of South Carolina Department of Disabilities and Special Needs (DDSN) includes assistance to “minimize the occurrence and reduce the severity of disabilities through prevention”. The **Prevention and Wellness Committee** leads agency efforts to monitor, coordinate, and expand activities related to prevention and health promotion. It includes representatives of policy, operations, and administration areas of the agency.

A variety of agency functions, as well as collaborative initiatives with other agencies and organizations, help support primary prevention of developmental disabilities and traumatic injuries, secondary prevention to reverse or ameliorate disabilities, and promotion of wellness and tertiary prevention of secondary debilitating conditions in populations served by DDSN. Surveillance of disability and injury, other data review processes, and interagency groups develop and monitor relevant prevention efforts.

**Comprehensive Genetic Services**

- DDSN Partnership with DHHS and Greenwood Genetic Center

DDSN contracts with the Department of Health and Human Services (DHHS) and subcontracts with Greenwood Genetic Center to make this statewide, multi-faceted program available to DDSN consumers/families and other Medicaid-eligible or potentially eligible persons who have or are at risk for acquiring genetically-linked conditions. Approaches to prevent the occurrence or reoccurrence of genetically-linked mental retardation and related conditions or metabolic disorders include early diagnosis, preventive treatments, risk assessment, genetic/preconception counseling, alternative reproduction, and prenatal diagnosis.

Genetics services provided by Greenwood Genetic Center include outreach and education, voluntary genetic testing, and voluntary genetic counseling. These are delivered statewide by four regional teams comprised of physician geneticists, Masters level genetic counselors, nurses and/or social workers, and clerical staff.

- South Carolina Center for Treatment of Genetic Disorders

Greenwood Genetic Center is currently operating and expanding this treatment facility. It works in concert with similar centers throughout the country as genetics research evolves, including treatments for specific genetic/metabolic conditions. The major focus is developing and providing effective treatments for conditions that cause or bring risk of mental retardation or other developmental disabilities.

There currently are established treatments for Phenylketonuria (PKU), Hypothyroidism, and 27 other metabolic conditions. Treatments are made available in South Carolina through the Metabolic Treatment Program, a partnership of Greenwood Genetic Center and DDSN. There are emerging treatments for Mucopolysaccharidoses and disorders of creatine metabolism. Treatments in the future are anticipated for Fragile X Syndrome and other disabling genetic conditions.

- **Neural Tube Defects (NTD) Prevention Awareness Campaign**

Regular use of folic acid by women of childbearing age is well proven to prevent Neural Tube Defects (Anacephaly, Encephalocele, and Spinal Bifida) from occurring or recurring in future births. "South Carolina NTD Prevention Awareness Campaign" is a partnership among Greenwood Genetic Center, South Carolina Developmental Disabilities (DD) Council, Department of Health and Environmental Control (DHEC), DHHS, and DDSN to promote knowledge of the prevention benefits of folic acid and increase folic acid use by women of childbearing age to prevent NTDs. This project receives ongoing DD Grant funding and oversight by the DD Council Health Committee. Educational and outreach materials are disseminated via media ads, billboards, and distribution of printed materials. A project representative visits physician's offices, medical clinics, and community health programs that target women of childbearing age to encourage NTD prevention. Outreach efforts also are made to school nurses and health/science teachers. College Advisory Boards conduct events on several college campuses to increase awareness and folic acid use. Bridal fairs are also effective forums for this.

## **Injury Prevention**

- **Relevance to DDSN and Head and Spinal Cord Injury (HASCI) Division**

Injuries to adults, youth, and children are significantly higher in South Carolina than in other states. Traumatic/acquired brain injury and spinal cord injury can result in developmental or other severe lifelong disabilities. Motor vehicle and bicycle crashes, falls, recreation and sports injuries, diving accidents, near drowning, airway obstruction, assault, and gunshot are frequent causes of brain damage and spinal cord injury. Brain Injury is a major cause of epilepsy/seizure disorder. Proper safety practices and avoiding high risk activities and behaviors can prevent serious injuries and subsequent disabilities.

- **Coordination with DHEC Division of Injury and Violence Prevention**

The lead agency for injury prevention in South Carolina is the DHEC Division of Injury and Violence Prevention, and DDSN coordinates with its efforts. A major priority is child and youth injury prevention. Safety information is disseminated statewide in English and Spanish. Injury prevention presentations that target children, youth, and families are made by DHEC staff in schools and other community settings.

The Division gets significant grant funding from the SC Department of Public Safety to promote prevention of injuries related to motor vehicle crashes. DHEC estimates 95% of children in car seats are not properly restrained and at risk of serious injury in even a minor crash. To promote proper use of child restraint systems, DHEC has “fitting stations” in four parts of the state and mobile units to reach many other areas. DHEC and SC Department Public Safety are partnering to educate families and childcare workers about correctly restraining children in motor vehicles. There is special outreach to the Hispanic speaking population.

- South Carolina Injury Prevention Strategic Plan

In 2006, DHEC was awarded 5-year federal grant funding by the CDC National Center on Injury Prevention and Control to enhance state efforts to link injury surveillance with comprehensive injury prevention initiatives. The project includes efforts by the state Budget and Control Board’s Office of Research and Statistics to aggregate/consolidate injury-related data within an “Injury Cube” that can be easily accessed to assist prevention planning and evaluation activities. An interagency planning group developed a 5-year strategic plan to prevent death and disability due to both unintentional and violent injuries. DDSN participated in this effort. The *Injury Prevention State Plan* outlines current and proposed prevention strategies and activities addressing major injury and violence issues.

- Safe Kids South Carolina – The Children’s Trust of South Carolina

Safe Kids South Carolina is an active state coalition (with affiliated local coalitions) of public, non-profit, and private stakeholders concerned with preventing childhood injuries. Previously hosted by South Carolina Hospital Association, since 2009 it is a component of the non-profit organization, The Children’s Trust of South Carolina. Safe Kids South Carolina is an affiliate of Safe Kids Worldwide, a global organization dedicated to preventing unintentional injuries.

Founded in 1993, Safe Kids South Carolina focuses on reducing injuries from motor vehicle crashes, promoting proper use of child restraint systems, teaching pedestrian safety, preventing falls, promoting bicycle, sports, playground, and water safety, preventing burns and poisoning, and promoting safe gun storage so children do not have access to firearms.

DDSN contributes funding each year to sponsor a page of the *Safe Kids Safety and Prevention Calendar*. Each month features an area of child injury prevention and includes a drawing by winners of a statewide art competition among school children. The calendars are distributed to every elementary school in the state and community organizations to promote injury prevention.

Beginning in 2010-2011, the *Safe Kids Safety and Prevention Calendar* extends from August-July of the following year to coincide with school calendars. It is also being expanded to provide more injury facts and safety information for children.

- DDSN Head and Spinal Cord Injury Division Injury Prevention Projects

Each year the HASCI Division funds modest community-based injury prevention projects selected through a competitive process. \$1300- \$5000 is awarded to help support collaborative community activities. The current focus is projects to develop and expand local *ThinkFirst* programs aimed at helping young children, youth, and teens learn about personal vulnerability and the importance of making safe choices. *ThinkFirst* curricula and materials are research-validated and have received national and international recognition. Projects funded in state fiscal year 2011 include:

- Florence County DSN Board  
*ThinkFirst of Florence County*
- Tri Development Center of Aiken County  
*Use Your Mind to Protect Your Body*
- Disabilities Board of Charleston County  
*ThinkFirst Colleton County*
- Medical University of South Carolina  
*ThinkFirst Injury Prevention Programs in the Low Country*
- *Babcock Center (Phoenix Services)*  
*ThinkFirst Columbia*
- South Carolina Spinal Cord Injury Association  
*Midlands ThinkFirst Chapter*
- South Carolina Brain Injury Association  
*Training and Support for ThinkFirst Health Educators and VIP Presenters*

### **Early Intervention:**

DDSN collaborates with First Steps and other state agencies in providing “BabyNet” services and other resources to infants and toddlers (birth to 3 years) who have conditions/diagnoses with a high probability of causing developmental delay.

DDSN provides Early Intervention services to eligible children from birth to age six years who have a genetic, medical, or environmental history indicating that they are at a substantially greater risk than the general population for developmental delay. A child may be eligible for both BabyNet and DDSN services. If a specific diagnosis remains unclear beyond 36 months of age, the child will be considered “at-risk” within the DDSN system and will be eligible only for service coordination and special instruction services.

Early Intervention services are designed to meet the developmental needs of at risk children. Parents are assisted so the family can enhance the child's development. Services build on existing child and family strengths to help in achieving outcomes that make a difference in the life of their child and the family. Services are provided in natural environments, including home and community settings in which children without special needs participate.

The Early Interventionist has the primary responsibility for Service Coordination to assist and support the child and family during the eligibility determination process, assessment, plan development, service delivery, and transition to school-based services and natural supports. The Early Interventionist also may function as a Special Instruction provider. Special Instruction is the design and demonstration of learning environments and activities which promote the child's acquisition of skills in a variety of developmental areas, including cognitive processes and social interaction. Special Instruction services are provided in a variety of settings, at a frequency that is agreed upon by a team of people who know and support that child and family.

Babynet and Early Intervention services can reduce the frustration, stress and isolation that families may experience and help young children with disabilities to become more independent. Services delivered in the context of the family can improve both the developmental and educational gains of the children served and may also reduce costs of future health care and special education.

### **Wellness and Health Promotion:**

- DDSN Health Care Guidelines

These are a comprehensive set of guidelines developed as a best practices resource for health care professionals in DDSN Regional Centers. The 4<sup>th</sup> Edition has been distributed. It includes new "Preventive Health Care Recommendations for Adults".

The DDSN Prevention Committee is promoting use of similar health care guidelines and prevention recommendations by local providers. The major focus is promoting good nutrition, weight management, increased physical activity, and preventive health care for populations served by DDSN. Efforts are made to educate and influence staff who directly assist consumers in residential and day settings.

- DDSN Medical Consultant Newsletters

Periodic issues of the newsletter address health promotion and illness prevention topics (e.g. recognition of illness, constipation, vomiting, influenza, high blood pressure, pneumonia, etc.). They are circulated to DDSN Central and District Office personnel, staff of DDSN Regional Centers, and local providers via the DDSN Website.

- South Carolina Disabilities and Health Project

Collaboration among the USC School of Medicine, Department of Family and Preventive Medicine, DHEC, and DDSN on a five-year wellness promotion and secondary disability prevention effort funded by the federal Centers for Disease Control and Prevention (CDC) National Center on Birth Defects and Developmental Disabilities. The South Carolina DD Council, through its Health Committee serves as the advisory body for this project.

Major objectives of the South Carolina Disabilities and Health Project are to:

- Analyze and disseminate disability-related data for South Carolina from the Behavioral Health Risk Factor Surveillance System
  - Promote wellness and prevent secondary debilitating conditions in persons with disabilities, including health awareness and education
  - Give technical assistance to clinic settings and physician's offices for providing people with disabilities full access to preventive health care
  - Increase capacity of local public recreation program providers to recruit and engage children with disabilities in a wide array of physical activities and sports
  - Provide technical assistance to public/private fitness centers and sports clubs to improve accessibility and encourage use by individuals with disabilities
  - serve as a CDC-designated "Mentor State" (one of six in the country)
- Steps to Your Health

As part of the South Carolina Disabilities and Health Project, the USC School of Medicine developed the Steps to Your Health (STYH) curriculum and demonstrated it to be effective in improving health and preventing secondary debilitating conditions in people with mental retardation and related disability. The STYH curriculum was also adapted for use with people with traumatic brain injury and similar disability.

STYH training and associated activities target nutrition, exercise, stress management, behavior modification, and communication as areas that people with disabilities can acquire knowledge and skills to maintain wellness. The goal is to achieve lasting positive lifestyle changes. Data is collected to demonstrate increased awareness and improved health practices by the participants.

DDSN is committed to incorporation of the STYH curriculum and approaches (or other evidence-based health education programs) into regular agency services and funding streams. It can be a component of Residential Habilitation, Day habilitation, Center-based or Individual Rehabilitation Supports, summer services, recreation programs, or self-advocacy group activities.

CDC awarded USC School of Medicine a separate 3-year federal grant to conduct a formal efficacy trial of the Steps to Your Health program beginning in October 2006. In partnership with DDSN and local providers, 450 adults with mental retardation, autism, or brain Injury were recruited and assigned to either an intervention group or control group. Eventually, all persons in both of the research groups were given opportunity to complete the Steps to Your Health program. Results of the efficacy study were positive and will be presented in several upcoming articles in professional journals.

### **Prevention Resources**

- DDSN Prevention and Wellness Resource Room

Located on the Midlands Center campus in Collaborative Building A, Room 19, the DDSN Prevention and Wellness Resource Room is managed by staff of the Head and Spinal Cord Injury Division.

The DDSN Prevention and Wellness Resource Room has general information about preventable developmental disabilities, traumatic brain injury, and spinal cord injury. There is also information related to wellness promotion and prevention of secondary debilitating conditions for these populations. There are resources pertaining to motor vehicle and child passenger safety, bicycle safety, recreation and sports safety, home and fire safety, choking and poisoning prevention, prevention of neural tube defects, healthy pregnancy and child development, nutrition and weight management, fitness, and exercise. Available items include prevention training curricula and materials, videos, booklets, fact sheets, posters, and promotional items.

Although resources of the DDSN Prevention and Wellness Resource Room are becoming depleted, it is expected these will be replenished when more funding is available in the future for prevention and wellness promotion efforts. A current priority is to provide incentive items (pedometers, water bottles, whistles, T-shirts, reflective decals, etc.) for DDSN consumers who participate in Steps to Your Health.

### **Surveillance of Disability and Injury**

- South Carolina Head and Spinal Cord Injury Information System

DDSN collaborates with the State Budget and Control Board Office of Research and Statistics, the Department of Health and Environmental Control (DHEC) Division of Injury and Violence Prevention, and Medical University of South Carolina (MUSC) Department of Biostatistics, Bioinformatics, and Epidemiology to implement statewide surveillance of hospital discharge and emergency room data to document incidence and associated factors of traumatic brain injuries and spinal cord injuries in the state. The system has operated since 1991, funded primarily by the federal Centers for Disease Control and Prevention (CDC) through grants awarded to DHEC.

- Autism and Developmental Disabilities Monitoring Network

MUSC has received funding since 2000 from the CDC National Center on Birth Defects and Developmental Disabilities to conduct surveillance of Autism Spectrum Disorders and other Developmental Disabilities in the Coastal and Pee Dee Regions of South Carolina. The study is part of an effort to establish national incidence and prevalence rates, track changes in rates, document co-morbidities, identify subtypes and high-risk groups, determine risk factors that may be modifiable, and document information to assist prevention and intervention activities. The South Carolina effort is linked to persons served by DSN Boards in the target areas.

- South Carolina Birth Defects Program

State legislation was passed in 2004 authorizing DHEC to operate an ongoing statewide system for surveillance of numerous birth defects, as most other states do. Funding to initiate the surveillance system was not appropriated until 2007. The program is guided by an interagency Advisory Committee which promotes identification and follow-up of children with birth defects, including appropriate treatment and services. DDSN is represented with this group.

In 2007, surveillance of Neuro Tube Defects, cardiac defects, limb reduction defects, and several other conditions previously conducted by Greenwood Genetic Center was transferred to the DHEC South Carolina Birth Defects program.

- South Carolina Behavioral Risk Factor Surveillance System

USC School of Medicine, Department of Family and Preventive Medicine collaborates with DHEC Division of Epidemiology in conducting and analyzing results of an annual telephone survey of a random sample of adults concerning health-related behaviors. Two questions are used to identify adults with disabilities within the random sample. An annual report is produced which contrasts responses of adults with disabilities to those of other adults.

### **Interagency Groups**

- State Child Fatality Advisory Committee

This group is mandated by state law to identify patterns in child fatalities to guide agency efforts to decrease preventable child deaths. Any unexpected death of a child under age 18 years must be investigated by the State Law Enforcement Department (SLED) and is categorized as natural, unintentional injury, homicide, suicide, or undetermined. The Committee reviews the SLED findings and issues an annual report. It also has a subcommittee that focuses on recommendations for child fatality prevention. DDSN is represented with this group.

- Trauma Care Advisory Council

Effective trauma care saves lives and mitigates long term disabilities. The Trauma Care System in South Carolina includes local Emergency Medical Services and Emergency Transport, four Level-I Regional Trauma Center hospitals, two Level-II Area Trauma Center hospitals, and seventeen Level-III Trauma Center hospitals. Rehabilitation Services, Injury Prevention and Education, and Research are also part of the system. South Carolina's trauma care system is now in serious crisis because of limited funding and resources along with increased state population and high rates of motor vehicle crashes.

In 2003, the General Assembly enacted The Trauma Care System Act to begin to systematically address the problem, establish a formal infrastructure, and promote more adequate funding. The state Trauma Care Advisory Council was also created to address policies and issues that affect trauma care. DDSN is represented with this group.

- South Carolina Injury Free Alliance.

DHEC convened the "South Carolina Injury Free Alliance" (SCIFA) in 2010 to coordinate injury surveillance and prevention efforts and advocacy by agencies and other relevant stakeholders at the state and local level. SCIFA supports efforts to inform the general public and educate target groups to promote injury prevention. It assists DHEC with implementing and monitoring the *Injury Prevention State Plan*. DDSN is represented with this group.

- South Carolina Eat Smart - Move More Partnership

This collaboration among government agencies was formed in 2007 by the merging of two previous groups (South Carolina Coalition for Promoting Physical Activity and South Carolina Obesity Prevention Efforts). The goal is a state in which healthy eating and active living is the pillar for healthy lifestyles in healthy communities. Partnership activities include communication, education and training, dissemination of resources, and advocacy. DHEC facilitates this partnership and provides staff support. DDSN is represented with this group.